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Personalized recovery of severe COVID19: Rehabilitation from the perspective of patient needs.

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After long term hospitalization or ICU treatment, COVID-19 patients are severely functionally impaired. They experience not only physical weakness but may also suffer from problems on the pulmonary, physical, psychosocial and cognitive domain. These domains interact and the impact on participation varies between patients. Therefore aftercare should be customized to the patients individual needs. In this article we present a patient centered model to tailor treatment in the view of the Dutch health care system. This model can be helpful to determine the appropriate treatment for each patient at the right time in the right setting

At this moment, the end of May 2020, we are reaching the tail of the first wave of COVID-19 infections in The Netherlands. The foundation for National Intensive Care Evaluation (Stichting NICE) and the governmental institution for public health and environment (RIVM) report 11.722 hospital admissions and a total of 2883 intensive care unit (ICU) admissions. A number of 1429 patients left the hospital alive after ICU treatment and 404 are still in hospital recovering from ICU treatment. The duration of ICU treatment is long with a mean length of stay varying from 14 days for non-survivors, 20 days for patients transferred to the hospital ward and 16 days for people discharged to 'other destinations'. Mean length of stay for patients still in ICU is currently an impressive 44 days (www.stichting-nice.nl; www.rivm.nl). It is estimated that 70%-80% of ICU survivors will face chronic problems that will affect daily life activities ¹. Models that predict the rehabilitation capacity needed for COVID19 patients are based on assumptions which impose a large uncertainty. Until now, in the post-acute setting of COVID19 infection wave, the rehabilitation capacity in The Netherlands has been sufficient.

Literature shows that 30-40% of patients requiring long term (>48 hours) ICU treatment with invasive ventilation experience severe and multifactorial limitations in different domains of functioning (physical, cognitive and psychological), known as Postintensive Care syndrome (PICS) ^{1,2,3}. The physical domain includes ICU acquired weakness and critical illness polyneuropathy and myopathy and has a prevalence of 25-80% ¹. The extreme inactivity and hyperkatabolic state due to severe illness leads to fat free mass depletion, muscle weakness, including respiratory muscles, and impaired sensibility and functioning of long nerve fibers. Prevalence of cognitive impairments is about 30-80%,

with impairments in attention, concentration, memory, processing and problem solving ^{1,4}. Psychological symptoms like anxiety and depression have a prevalence of about 30%, and 10-50% of the patients report symptoms of Post Traumatic Stress Disorder ^{1,5,6,7,8}. It is also important to pay attention to the needs of caregivers who were exposed to extreme stressful and traumatic circumstances. They can experience severe physical and psychological symptoms in almost similar prevalence numbers shown by ICU survivors, a syndrome known as PICS-F ^{1,2,9}. Patients (and caregivers) in our postCOVID-19 rehabilitation clinic show complex problems in all above mentioned domains in similar prevalence mentioned in literature. Severe COVID-19 results in respiratory insufficiency, mainly severe hypoxemia, primarily due to viral pneumonia. Patients need high levels of oxygen suppletion or even long term invasive ventilation. In our Centre of Expertise for Complex Chronic Pulmonary Disease we are used to work with people with chronic pulmonary disease. Now we admitted patients without a medical history of pulmonary disease in an acute phase who experience the vicious circle of severe shortness of breath for the first time in their life resulting in fear, anxiety and dysfunctional breathing. Patients presented with complications of the COVID-19 associated coagulopathy like venous thromboembolism and pulmonary embolism. COVID-19 induced hypercoagulability can also lead to cerebral infarction. We did not get these patients referred to our clinic up to recently. One third of our patients showed neuropathy of long nerves due to anoxia amongst other factors. Anoxia may also lead to postanoxic encephalopathy and there is evidence suggesting the existence of COVID-19 encephalitis as well ¹⁰. About 25% of our patients report changes in or loss of sense of smell and changes in taste. In COVID-19 there are multiple possible causes for cognitive impairments. Frequency, severity and prognosis in relation to pathophysiology are not yet clear ². We recognize that patients report hallucinations caused by delirium, forgetfulness and reduction in the ability to concentrate. Emotional consequences should not be underestimated. All our patients face problems in processing what happened to them and their loved ones. We suspect that the incidence of pulmonary complications, cognitive impairments and emotional problems will be higher and more severe in the COVID-19 patients than in other PICS-patients. This might be caused by the exceptional long period of ICU treatment with invasive ventilation and strict isolation measures. A timely and patient tailored rehabilitation is needed to help these patients to return to societal

participation. The rehabilitation trajectory can be subdivided in three phases: The acute phase, the subacute (inpatient) rehabilitation phase and the long term (in- or outpatient) rehabilitation phase.

In the acute rehabilitation phase the patient is recently detubated and has to reactivate in an hospital ward. Organ function is recovering and the patients undertake their first steps towards regaining their independency. In the subacute (inpatient) rehabilitation phase the patient is medically stabilized and indication of hospitalization is expiring. Some of these patients recover fast and can directly be discharged from hospital to home. Others are severely impaired and far away from their premorbid functional status. These patients need inpatient rehabilitation aimed at regain of functional capacity that is minimally needed to go home after a long period of hospitalization. This period can be complicated by the patient still shedding virus and being infectious, although the period of being infectious becomes clearer and might be shorter than previously suspected. Most patients reach a functional level in which they can be independent in physical functioning, self supporting or with some help from loved ones or professionals. If problems persist in the long term on different domains of functioning, an in- or outpatient rehabilitation can be indicated.

The complex multifactorial pattern of disabilities after COVID-19 requires tailored therapy at the right time and the right place. Not only for patients discharged from hospital to a rehabilitation clinic, but also for patients that were directly discharged home or those that weren't even hospitalized at all. There are signals that these patients with "mild COVID-19 disease" may also suffer from severe complaints in multiple domains and also those patients can benefit from rehabilitation programs. Starting point for these programs should be the individual care needs and participation ambition.

Treatment options in The Netherlands

The Dutch care system provides different options for offering specialized care to severely impaired COVID-19 patients. Mapping the individual treatable traits that hinder participation is the first step in our model. The Venn diagram in figure 1 shows that severe COVID-19 can lead to problems in different domains: pulmonary, physical, psychosocial and cognitive domain with interfering comorbidities taken into account.

Problems in overlapping domains will prevail more often than problems in a single domain which underlines the need for tailoring treatment. An assessment based on these domains and overlap can help direct referral and treatment of patients.

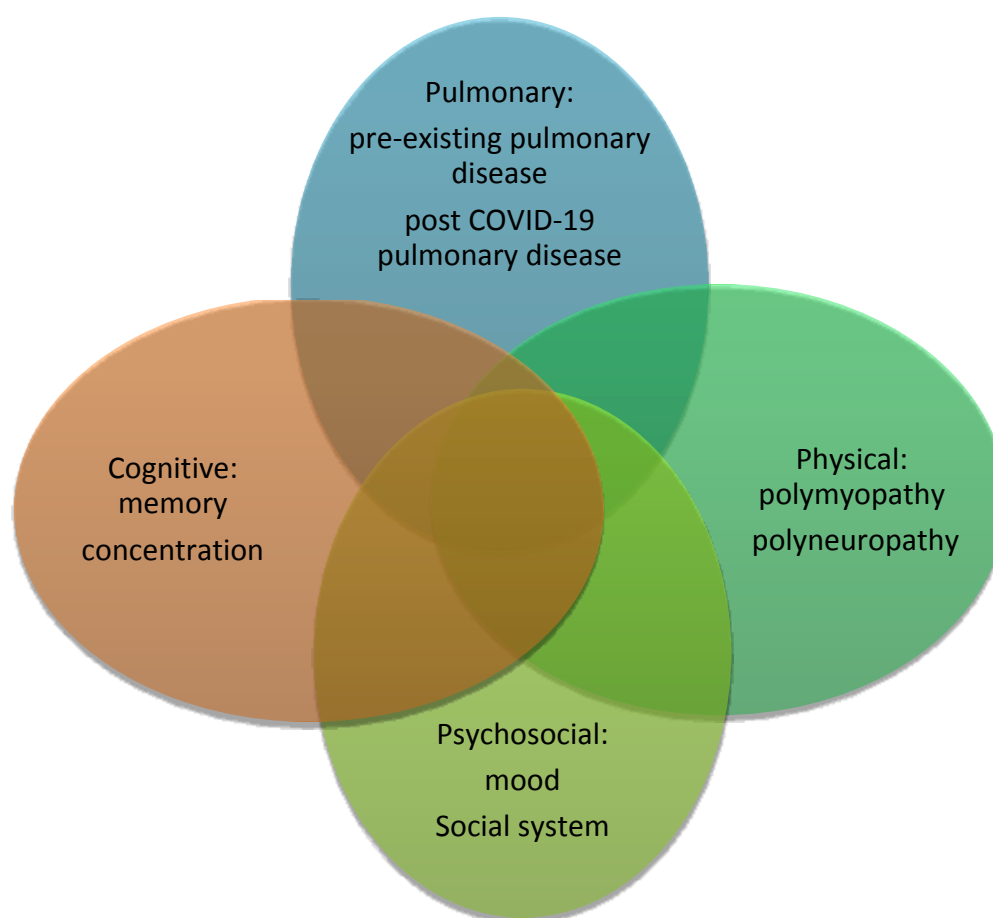


Fig. 1: Assessment model for planning after care in severe COVID-19

Pulmonary Domain

Within the COVID-19 group of patients there will be patients with pre-existing pulmonary disease and patients without pre-existing pulmonary disease that are still respiratory insufficient and needing oxygen suppletion or experiencing breathing difficulties that hinder physical activity. Whether COVID-19 will lead to severe lung damage or a chronic lung disease is not known by now. That makes it difficult to predict the influence of treatment and the duration of rehabilitation needed.

Our clinic offers inpatient pulmonary rehabilitation and treatment is based on assessment of all domains of the assessment model. Our sub-acute inpatient postCOVID-19 program

is aims at a rapid discharge home, with or without extra professional help. The assessment is helpful in setting individual treatment goals, evaluation of progress and clinical decision making. Treatment is multidisciplinary using a interdisciplinary approach under the responsibility of a pulmonary physician. We expected a relationship between duration of ventilation in ICU and duration of rehabilitation program but up to now this is not clearly visible. In a cohort of 15 patients duration of ventilation varies from 6-27 days and duration of our subacute inpatient postCOVID-19 rehabilitation, with the treatment goal mentioned above in mind, varies from 8-29 days with an average of 17 days.

In The Netherlands we have five Centers of Expertise for Complex Chronic Pulmonary Disease (Merem, Hilversum; Beatrixoord, Haren; Ciro Horn; Dekkerswald, Nijmegen and Revant, Breda) that offer personalized rehabilitation programs for patients with chronic lung disease. If in the long term follow up treatment in one of these centers seems obvious for post COVID-19 patients who are limited in daily life activities mainly due to pulmonary factors interacting with physical functioning and/ or psychological or psychosocial limitations..

Physical domain

In patients that have mainly physical limitations, assessment of rehabilitation needs can be made on the clinical presentation of symptoms. Outpatient rehabilitation is possible in cases with adequate level of functioning in the activities of daily live. Depending on the level of coexisting cognitive and emotional dysfunctioning a choice can be made between first line physiotherapy under supervision of a general practitioner (GP) or an integrated treatment program in a specialized rehabilitation clinic. Using the expertise of a specialized rehabilitation physician can help the GP make the right choice for their patient.

Inpatient specialist rehabilitation treatment is indicated for patients with high levels of premorbid participation and high level participation goals. Patients with pre-existing low levels of functioning, with severe interacting comorbidities that hamper physical training or with low-level participation goals are better of in geriatric rehabilitation or reactivation programs

Cognitive domain

Special attention should be paid to cognitive problems because they can be difficult to detect. Severe cognitive limitations are mostly obvious but milder limitations can be hidden until more complex tasks that need more complex cognitive abilities are to be performed. Therefore adequate screening is needed. The Dutch association of rehabilitation physicians (VRA) and the association of geriatric care specialists (Verenso) recommend the use of the Montreal COgnitive Assessment (MOCA) as a screening instrument in all patients ^{11,12}. In case of aberrant test-results or in case of subjective cognitive impairments neuropsychological can be considered.

Cognitive rehabilitation in The Netherlands is offered in the 18 larger specialist rehabilitation clinics.

Psychosocial problems

It is important to realize that cognitive impairments can present as or mimic emotional or neuropsychiatric symptoms. The other way round is that complaints about cognitive functioning may indicate emotional problems. The VRA and Verenso advise all COVID-19 after-care outpatient clinics to screen for both emotional and cognitive problems. If needed, a rehabilitation physician can be consulted about treatment options. Patients and caregivers mainly dealing with emotional and psychological impact of COVID-19 disease will primarily consult the PG, but referral to specialized mental healthcare may be needed.

Conclusion

After severe COVID-19 patients can experience a wide array of problems. Patient centered and tailored therapies need a thorough assessment of underlying problems. Assessment and analysis of pulmonary, physical, psychosocial and cognitive domain and interactions can be helpful for referring the patient to the right care at the right time. Rehabilitation physicians can be consulted for helping doctor and patient through this diagnostic process. If pulmonary limitations are the most important factors interacting with physical functioning and/ or psychological or psychosocial limitations, treatment in a Centre of Expertise for Complex Chronic Pulmonary Disease or pulmonary rehabilitation centers is of added value.

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Casus 1

A woman, aged 58 years starts her rehabilitation after hospital admission for COVID-19. She spent 22 days in hospital of which 6 days of invasive ventilation in the ICU. Before admission she was already 21 days ill at home. In her daily life she works as a hairdresser and has an active lifestyle. Medical history is restricted to abdominal and gynaecological surgery more than 4 years ago. At arrival at our centre she is still respiratory insufficient requiring oxygen supplementation at rest and on exertion to maintain adequate oxygenation. Pulmonary auscultation reveals bilateral basal crepitations up to 3/4 of the thorax. She suffers from shortness of breath and a dry cough, mainly related to exertion but shortness of breath can also be observed while talking. Weight loss is about 3 kilograms. Functional level at admittance is limited to making a transfer from bed to chair without help but with a lot of effort. Muscle weakness and shortness of breath/dysfunctional breathing are the main limiting factors. Emotional impact was immense. During her hospitalization and stay at the ICU her mother died of COVID-19 and was buried which she heard afterwards. Screening for anxiety and depression was negative. Although in the cognitive domain she reported problems in concentration, experiences feelings of confusion that makes her feel insecure. Detubation was a traumatic experience. Also her loved ones lived through an emotional intensive period but they form a healthy social system in which they support each other well. After 15 days of an intensive rehabilitation program with reduction of oxygen supplementation until stop, education and therapy aimed at regulation of breathing pattern and pace on exertion, cough techniques and training of muscle power and endurance and balance she could be discharged home being independent in activities of daily life. Adequate pace regulation prevents desaturations and using these techniques she is able to walk the stairs at home. Cognitive problems seemed to resolve spontaneously. After care is provided by local physiotherapist and the after care outpatient clinic of the hospital where she stayed. It is stressed that special attention should be paid to, of course, recovery of pulmonary function but also to cognitive and psychological symptoms in the long term. And also the long term effect on processing this intense life event for family members should not be forgotten.

Casus 2

A man, 62 years of age, started rehabilitation after hospitalization for COVID-19 for 32 days, after being ill at home for one week. Because of respiratory insufficiency he required prolonged invasive ventilation in the ICU for 24 days. In his everyday life he has a full time job as a technical engineer and has an active lifestyle. Medical history reveals depression 8 years ago and essential arterial hypertension. At admission to our clinic he is still on oxygen therapy using 5L/min and auscultation reveals bilateral basal crepitations. He suffers from a dry cough and breathlessness on exertion. At rest a rapid shallow breathing pattern can be observed, suggesting dysfunctional breathing. His ICU stay is complicated by thromboembolic complications such as venous thrombosis in both legs of which the left leg also showed signs of erysipelas at admission. His coccyx showed a small pressure ulcer. ICU acquired weakness was severe and functional level at admittance was limited to turning himself in bed and sitting upright using the side rails of the bed. Peripheral neuropathy is expressed in loss of sense in both feet. At admission he was still on haloperidol treatment because of delirium during hospital admission. He felt extremely insecure and anxious. Afraid of starting physical exertion and to reduce oxygen dose after negative experiences with physical therapy in hospital. Prior to transfer to our clinic his urinary catheter was removed and as a complication he developed urinary retention, which added to his sense of insecurity. He reported re-experiencing, having nightmares and flashbacks of his delirium, hyperarousal and insomnia and the outcomes of testing suggested Post Traumatic Stress Disorder (PTSD). Despite of his disease history he reported no cognitive symptoms, confirmed by negative testing. Sometimes he expressed somber feelings related to the disease process and not like his former depression. In the treatment period the combination of intensive medical care, stepwise building up physical training starting with Neuro-muscular electro stimulation (NMES), targeted nutritional intervention, reducing oxygen dose with the support of a highly trained and specialized team understanding the complex relationship between fear and anxiety and limiting factors in mobilization led to slow but progressive physical and mental recovery. Finally after 29 days of rehabilitation, oxygen dose could be reduced to 1L/min on exertion and he was able to walk the stairs using energy saving and breathing techniques. Follow up out-patient rehabilitation was planned and pulmonary follow up

appointments were made at the referral clinic. At a follow up contact 2 weeks after discharge he reported that he still felt extremely weak and tired and his story suggested that there might still be problems in acceptance and anxiety. This illustrates that adequate rehabilitation can be a long process and underlines the need for patient tailored therapy with trained professionals.